

Melissa Fortin-Beaudin

March 18, 2014

My name is Melissa & my son Dillon is 7yrs old with Down syndrome and PDD autism. I became a single Parent when Dillon was 2. Ever since then, I have been Dillon's only caretaker. I am also disabled but used to work at the UConn Health Center. I do not receive any child support income and live off of our Social Security income and long term disability. We are also not on welfare. Dillon is a 1st grade student in Farmington and is adored by the community.

Dillon has had 3 heart surgeries, gastric feeding tube since he was 2yrs old, compromised immunity that has resulted with numerous hospitalizations, asthma, behavioral issues, feeding disorder and much more. All of these conditions have resulted in hundreds of appointments & procedures in various parts of CT, including Boston. During all of this, I have worked vigorously in finding the providers that have had the experience that it takes to treat my child successfully.

Throughout Dillon's early years, he has had chronic eating issues. He has never been able to eat any solids and continues on eating pureed foods only. When he was 2yrs old, I started the journey with feeding therapy services. I brought Dillon to CT Children's Hospital to meet with their Feeding Team. I quickly discovered how their form of Feeding Therapy was not the right fit for my son. Their recommendations just did not work. We took some time off of CCMC's Feeding Therapy program and tried again, but only to find how they still could never get my child to chew. We had also tried feeding therapy with his school, however, the therapists too could not get my child to chew.

I then found a Feeding Therapist expert that had what it takes. Jennifer Hoskins has been extremely successful in getting kids off of feeding tubes but she doesn't participate with any insurance. One must pay out of pocket for her services for she is self-employed. She chooses not to participate for insurance reimbursements are not enough. She is very well known in our special needs community. She has an office in Rhode Island and in Marlborough CT. People travel long distance for she is the only therapist that has effective therapy skills. It took a few

years, but I finally was able to pay for 7 therapy sessions last summer. I applied for several grants but was denied. I even tried submitting to our Husky Insurance, however because she does not participate, they too denied. So after 7 very successful sessions with Jennifer Hoskins, Dillon had to stop getting therapy. It's been heart breaking to see Dillon finally able to eat solids to then totally regress because his therapy sessions had to stop due to my financial circumstances.

Being Dillon's Mom is an incredible gift in so many ways. However, seeing my child go without the help that he so desperately needs has been extremely hard. Seeing him with the failure to thrive diagnosis all of his life has not been easy. I also find it very disturbing how the State of Connecticut would rather see my child live with a feeding tube/formula for the rest of his life rather than getting the appropriate therapy services. Dillon deserves a chance to eat and thrive just like a typical child. My request is for DDS or the State of CT to give families like mine an opportunity to get funding so we do not need to live without services that can be life changing.

Respectfully yours,

Melissa Fortin-Beaudin